# ASCF Announces Sandra Turner Memorial Scholarship

The Arkansas Spinal Cord Foundation (ASCF) is pleased to announce the first Sandra Turner Memorial Scholarship. The \$1,000 scholarship will be awarded to an Arkansan who lives with a spinal cord disability and is pursuing a college degree or other vocational training pursuit.

"This scholarship is consistent with the mission of the Arkansas Spinal Cord Foundation, to promote the health, well being and quality of life of Arkansans with spinal cord disabilities" notes ASCF President John Wyrick, "we are pleased and excited to provide this opportunity to a young person, as well as to honor Sandy Turner."

The scholarship is named for Sandra Turner, a long term member of the Arkansas Spinal Cord Commission and a founding member of the Arkansas Spinal Cord Foundation. Ms. Turner, who lived with a spinal cord injury from a motor vehicle crash, was the President of the Foundation until her untimely death in 2009. Sandy had an infectious positive attitude about her disability and promoted the Foundation as a way to provide funding for services for those who needed help to achieve their goals.

The first scholarship will be awarded in August, in time for the start of fall semester. Eligibility requirements include:

- Arkansas resident
- Lives with a medically documented spinal cord disability (i.e. spinal cord injury, spina bifida, multiple sclerosis)

- Has been accepted to a college, university or vocational training program for the fall semester
- Complete and submit an ASCF Sandra Turner Memorial scholarship application and required documents by June 15, 2012.

If you would like to apply for the scholarship, an application is available on the ASCC website at www.spinalcord.ar.gov.

For additional information contact:

Mike Cranford ASCF Scholarship Selection Committee mcranford@whti.net 903-826-3318

# TV Ads for Wheelchairs... Why NOT?

The next time you see a commercial on T.V. about getting a new wheelchair for little or no cost, think twice before picking up the phone to dial that number. Contrary to popular belief, one size does not fit all!

If you have a spinal cord disability, you should be evaluated for a proper fitting wheelchair that includes a team approach including an Occupational and/or Physical Therapist, a physician and a representative from a durable medi-

cal equipment provider / company (vendor). This company should have an Assistive Technology Professional (ATP) on staff. You, and a caregiver if you have one, are also an important part of the team.

One client who used a 'TV company' was told "this is all your insurance will pay for." Contrary to that statement, what a vendor says 'your insurance will pay for' might be different from what they can bill to your insurance (including Medicare and Medicaid). If the vendor

you chose to use does not have an ATP on staff, they should have told you "this is the equipment we are allowed to bill to your insurance." For many insurers, including Medicare, if you do not have an ATP on the team, you cannot get a custom wheelchair.

The hard part is you are pretty much "STUCK" with that T.V. wheelchair for a MINIMUM of 5 years. The old 5 year rule no longer applies and it could be 7, 8, or

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#### SPINAL CONNECTION

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Cheryl L. Vines Executive Director

Jason Francis Editor

Commission Members: Jon Wilkerson, Chair Mike Cranford Annette Stacy Ronnie Wheeler John Wyrick

The Arkansas Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

Visit our website at:

### www.spinalcord.ar.gov

or e-mail us at: ascc@arkansas.gov

### With Thanks

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Paula Mills
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In Memory of James K. Massery

ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and educational resources.

To make a contribution, please contact ASCC at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

## From The Director

How do you like our new look?

After 22 years as that blue Spinal Courier, new Editor Jason Francis and his editorial team decided it was time for a change. A long overdue change. After looking at our many options, we decided to move to a more recyclable, white newsletter. I hope you will be able to find it in the mail (that's why we stayed with blue so long!).

Along with the new look comes a new name. The Spinal Connection. The Courier served us well, but the Connection is what people with spinal cord disabilities are about in 2012, connected, in touch, with energy and movement. We want this to be one of your connections, hooking you up with new, cutting edge information and resources.

My thanks go out to Editor Jason Francis and our new editorial team, Bob Johnson, Elouise Kemp, Terra Patrom, Stephanie Prewett, Patti Rogers, Gwen Winston and Janet White – they are all committed to bringing new information and ideas to the Connection. While I'm thanking folks – a big thanks to Greg Lemke, from Gentry, AR, for volunteering to write some articles for the Connection – his first is on page 5. We need articles and ideas from the consumer perspective, so please; if you have an idea or an article, let Jason know. The Connection will get better with every issue!

What else is new at ASCC? We have entered an agreement with the Arkansas Trauma Advisory Council (TAC) to develop the rehabilitation component of the state trauma system. These efforts will assure that rehabilitation programs and services are available and accessible to Arkansans who sustain severe traumatic injuries. It's a big project!

To spearhead our efforts, former ASCC Hot Springs Case Manager Kim Brown has moved into the position of TAC Rehabilitation Program Manager and will be working with ASCC and TAC Rehabilitation Committee Chairperson Jon Wilkerson to develop a strategic plan and carry out efforts to assure that rehabilitation is a key component of the trauma system. Kim brings her knowledge and experience as a Case Manager as well as her experience working in rehabilitation centers in Texas and California to her new position. I cannot think of a better person to lead these efforts for ASCC. Brad Caviness came on board last month to work with Kim on the project. We will keep you informed of our efforts.

Enjoy the beautiful spring!

Cheryl L. Vines

### **Get Your Wheels in Motion Playing Tennis**

Wheelchair Tennis is available in Fort Smith at the Fort Smith Athletic Club (FSAC). The FSAC provides outdoor courts during the summer at no cost and during the winter assists with reduced indoor court fees.

A certified United States Professional Tennis Association (USPTA) instructor with 10 years of wheel-chair instruction experience provides tennis instruction at no cost as a courtesy of the FSAC.

Currently, the program meets

weekly on Tuesdays for 1.5 hours of instruction and play.

Wheelchair tennis is open to men and women of all ages, all degrees of disability and there is no need for prior tennis experience. What is needed is the desire to play. Three wheeled chairs are preferred for better mobility and court coverage but are not necessary to participate.

In the fall of 2011 FSAC sponsored a wheelchair tennis roundup. There were four chair participants who played singles. They also had

mixed run-roll doubles afterwards. FSAC would like to repeat this event this fall with hopefully more participants.

To promote the program, we need:

- More wheelchair tennis players in Arkansas.
- Sources of funding for equipment. Chairs are expensive and locals use their basketball chairs.
- Sponsors for wheelchair tennis outreach programs.

For more information contact Ed Newlin at FSAC 479.452.4031 or 479.452.5269

#### Feel the Burn

By Lola Alapo, University of Tennissee

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Staying fit and healthy is a challenge for everyone, and a new study finds burning a few extra calories isn't that tough to do for people in wheelchairs.

An article written by David R. Bassett Jr. of the Department of Kinesiology, Recreation and Sport Studies at the University of Tennessee, shows a person who uses a manual wheelchair can burn up to 120 calories in half an hour while wheeling at 2 mph on a flat surface. That is three times as much as someone doing the same action in a motorized wheelchair. The same person in a manual wheelchair expends 127 calories while mopping floors for 30 minutes.

The article, which Basset co-wrote with former UT graduate student Scott A. Conger, was published in Adapted Physical Activity Quarterly, a journal issued by Human Kinetics, Inc. It calculates the calorie costs of various physical activities for people who use manual wheelchairs and summarizes them into a first-of-its-kind list.

"It might be simply wheeling their chair along while taking their dog for a walk or playing wheelchair basketball," says Bassett. "You can still burn a significant number of calories."

Bassett co-wrote another document entitled the 2011 Compendium of Physical Activities for able-bodied people. The study, which was funded by the National Institutes of Health, contains a list of activities that is continually updated and is widely used. But he saw a need to develop a comparable resource for those who use wheelchairs.

Bassett and Conger reviewed more than 250 studies containing energy expenditure data for wheelchairrelated physical activities. They identified 63 activities, ranging from being sedentary to household chores and transportation to exercise.

A partial list of wheelchair-related activities and their caloric burn (preformed by 160-pound adult in 30 minutes):

Dusting – 65
Table tennis – 80
Vacuuming – 98
Tennis – 149
Basketball – 221
Nordic sit-skiing – 428

# Sign Up for Spina Bifida Camp!

This week long residential camp for children ages 6 to 16 is located at Camp Aldersgate, a quiet, rustic area in west Little Rock near Baptist Health Medical Center. ASCC clients with any type of spinal cord disability are welcome. There is no fee for this week of camp.

This year's camp is scheduled for June 17 through June 22, 2012, but you need to sign up now.

We only have room for 40 campers, and acceptance is based on a first-come, first-served basis. The application deadline is May 15, 2012.

Camp activities include: campfires and singing, canoeing, fishing, arts and crafts, swimming, and nature hikes. Activities that focus on challenges include an accessible challenge ropes course, hand and/or foot driven catamarans, adapted archery, and a big hit with older campers, SCUBA diving.

Applications and brochures were sent out in March. If you have questions or need an application, call Mary Jo Stanton at 501-296-1788 or 800-459-1517 or e-mail at maryjo.stanton@arkansas.gov.



# **Spinal Stenosis**

By Tom Kiser, M.D., ASCC Medical Director

The word "stenosis' comes from the Greek word that means "narrowing" or "choking", so when you hear the term "spinal stenosis", it means that the spinal cord or the spinal cord nerve roots are getting pinched or squeezed. The signs and symptoms which develop depend on where the spinal cord is getting extra pressure.

The two most common areas of spinal stenosis are the cervical (neck) and/or lumbar (low back) regions of the spine, usually because these two areas have the most motion when we twist and turn. As we age, this extra motion causes degeneration and arthritis of the joints and supporting ligaments of the spine. The result is a slow, steady narrowing and compression of the space around the spinal cord and the nerve roots, and eventually a decline of nerve function. However, in the case of a herniated disk. a sudden loss of function can occur when the spinal cord or a nerve becomes pinched by the herniated and suddenly enlarged disk.

Cervical stenosis can cause both arm and leg problems, while lumbar stenosis only causes leg problems, both can cause bowel and bladder urgency and accidents. I will discuss lumbar stenosis first, and then we will turn our attention to cervical stenosis.

Lumbar stenosis can occur rapidly, in the case of a herniated disc, or slowly over time as the spine slowly degenerates and the joints and ligaments enlarge with degenerative changes, compressing the spinal cord and its nerve roots. This compression results in weakness and pain in the legs and gradually walking becomes more difficult; first a cane is required, then a walker, and eventually a wheelchair. The medical term used

to describe this progressive decline is "neurogenic claudication".

Claudication, literally means "limping' in Latin, which describe the symptoms well. People with this problem start to limp and develop fatigue and aching in their legs, and the distance they walk and the quality of their gait slowly declines. The gait pattern with neurogenic claudication is usually a forward flexed posture, with a decline in the person's ability to sense where their feet are without looking at them.

The term, neurogenic, means these symptoms are related to the decline in nerve function, and distinguishes



it from a similar but different condition called "vascular claudication" which is caused by loss of blood supply to the legs and can look very much like a person with stenosis of the spinal cord, as those people also limp and have leg pain. The difference is that the person with neurogenic claudication can usually get immediate relief of the pain and fatigued feeling if they lean forward at the waist or sit down, because that opens up the spine and often relieves the area of stenosis, whereas the person with vascular claudication must stop moving to allow the blood supply to catch up with the demands of the muscles, which usually takes a little more time.

The treatment for lumbar stenosis, when it starts to cause problems,



ASCC Medical Director Tom Kiser, M.D.

is to decrease the area of tightness on the cord and nerves. The treatment options can be conservative, therapy such as using a flexed spine position and strength training to open up the area of tightness. Sometimes the addition of a brace or corset can help with posture and medications such as nonsteroidal anti-inflammatory drugs (i.e. ibuprofen) or opiates can provide some relief. More aggressive treatment options are injections into the epidural space with steroids to reduce inflammation and swelling of tissue, surgical decompression with a removal of bone and/or soft tissue, or the addition of spacers or metal hardware to decrease the pressure on the cord or nerves.

Cervical stenosis can cause neck pain and shoulder/arm pain as well as poor coordination with hand activity and a decline in functional ability to use the arms and hands. Similar symptoms can affect the legs, but cervical stenosis can also cause spasticity because it is affecting the nerves in the central nervous system, where as in lumbar stenosis the nerves are often compressed after they leave the central nervous system.

An electrical shock-like sensation in the neck, radiating down the spine or into the arms, called "Lhermitte's sign" can be produced by forward flexion of the neck. Cervical Stenosis can increase the risk of spinal cord injury with minimal trauma such as a fall or a minor fender bender in a motor vehicle, so your doctor may

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## Spinal Stenosis

recommend surgical decompression to avoid future problems which can develop with minor trauma. The C5-7 regions of the spine are most commonly affected, and the injury to the cord, called "Myelopathy."

Myelo (spinal cord) Pathy (disease) is caused by direct compression of the cord, loss of blood supply (ischemia) due to compression of blood vessels supplying the cord, and/or repeated trauma with normal flexion and extension of the neck.

Treatment options for cervical stenosis also range from conservative to aggressive measures. Conservative measures often require a reduction in high-risk activities that cause you to move your head a lot or might put you at risk of falls.

We recommend airbags in your vehicles, and a head rest that is raised to provide support to the back of your head in case you are in a car accident. Sometime a neck brace is recommended if your doctor wants to be very safe. Medications to provide pain relief can be used, as mentioned above, and sometimes antiseizure medications to relieve nerve pain are added.

If the conservative measures are not enough or the condition is worsening the next step is surgical decompression with either a posterior (from the back) approach to remove some posterior bone to widen the spinal canal, or an anterior (from the front) approach if there is an anterior area causing compression. Sometimes both methods are required.

There is no consensus regarding the indications and timing for surgical treatment, so an in-depth discussion with your doctor and surgeon is required to discuss the risks of surgery and the expected benefits and outcomes from the surgery.

### It Never Hurts to Ask

From time to time we all stumble upon something that makes our lives a little easier or learn new ways of dealing with problems. We also have lots of questions on how others in our position deal with obstacles due to paralysis. For these reasons I have agreed to share some of these with the readers of the newly named Spinal Connection.

The first help I wanted to share is using our state agencies. Many have been introduced and get assessed but fail to use them to our fullest benefit. Here is the honest truth, always ask. The worst they can do is check and tell you no. No skin off your teeth. I can testify that they will look into your request and get back to you. It may not always be as fast as you would like and you might have to call your contact a few times but you will get an answer.

A lot plays into the decision making process such as the years funding and the time of year you make a request. This last year I asked my Spinal Cord Commission representative if it would be possible to get a backup battery for my power assist manual chair. They are quite pricy.

She did her thing and came back with a "no" answer but clearly gave me the reasons why they could not. She also let me know that we could try again next year and maybe they would have a bigger budget.

That was on the down side but here is one for the up side. A few years back I had this idea to ask Vocational Rehab for gate openers. I raise cattle but always had to find some one to go with me to check them so I could get the gates open.

Vocational Rehab assist people get back into a working environment and gate openers would greatly help in my job. So I asked not expecting much. My rep said, "we have never done anything like that but lets try it".

Soon they were here evaluating the request and with a little negotiations, boom, I had gate openers. Now I spend time checking for newborn calves with out bothering anyone.

The message here is, if you need help with something, ask! These programs are to help us. At times it doesn't seem like they do enough but other times you are glad they are there. By asking we can also let them know the needs that are out there and they can pass these along for future budgeting and such.

Greg Lemke Gentry, AR

# New Employees Arrive At ASCC

Bruce Kelley began his Case Management orientation and training in March replacing long time Batesville Case Manager Leetha Wren who retired in February. Bruce obtained his Master's degree in General Administration from Central Michigan University and is currently working on a Master's in Rehabilitation Counseling. He also served his country in the USAF for 17 years.

Bruce previously spent 10 years as a Rehabilitation Counselor with Arkansas Rehabilitation Services. Bruce is very familiar with the areas his ASCC clients live in and has already begun contacting many of them.

Bruce and his wife Peggy are Batesville residents. According to Bruce. He spends a lot of quality time with his two and four year old grandsons. "We had a cat but it moved out so I guess things must have been too hectic for him."

Diane Francis also began her orientation and training in March, replacing Hot Springs Case Manager Kim Brown who received a promotion and is now the Program Manager for the Trauma Rehab Program.

Diane recently completed her internship in the Rehabilitation Program at Arkansas Career Technical Institute and received her Master's Degree in Rehabilitation Counseling at UALR. "Diane brings excellent experience in customer service and facilitating group communications", Ms. Rogers stated. Diane has also begun contacting individuals on her caseload.

Diane enjoys crafting and loves riding motorcycles and kayaking and says it's her "Zen thing." And of course having six dogs and one chicken is another story.

Bradley Caviness joined the ASCC staff in March as the Administrative Specialist III in our newly created Trauma Rehabilitation program. He will be working with Rehab Program Manager Kim Brown and the Trauma Advisory Council Rehabilitation Subcommittee to develop and implement strategic plans and programs for the rehabilitation component of the trauma system.

Brad brings strong educational and work experiences to his new position. He holds degrees in English and Journalism for Southeast Missouri State University. His work experience includes Academic Affairs Coordinator at Philander Smith College and as an Executive Assistant at the Heifer Foundation.

Living in Little Rock, Brad is a movie aficionado and enjoys reading and music.

Kim Lewis joined the LR Case Management office in January. She will be providing Administra-

tive Specialist support to Case Managers Doug Fish and Zakeyieh Dissi Filat. Kim is a career state employee, having worked for UAMS for 19 years in the Radiology Department. "Kim's experience in the medical field has been a great asset to our agency", stated Client Services Administrator Patti Rog-



Diane Francis and Bruce Kelley

She is currently attending UALR working on her BS in Business Administration. Between working, studying, and attending classes Kim stated, "I have no life!"

But she does manage to assist her husband Carl with his business in addition to raising three children ages 22, 21, and 13. Kim, Carl and their three children live in the Little Rock area.

Kim loves to read, listen to music and travel when opportunity arises. She is planning her next trip to New Orleans.

Please join the ASCC commission members and staff in welcoming our new employees!



Kim Lewis and Bradley Caviness

### **ICAN Increasing Capabilities Access Network**

ICAN AT4ALL is Arkansas' statewide Assistive Technology program designed to make technology available and accessible for everyone who needs it. ICAN AT4ALL offers a number of services to help Arkansans of all ages find the Assistive Technology they need for home, school, work and getting around in the community.

ICAN services include:

- Information and Referral
- Equipment Loans
- Equipment Recycling
- Equipment Exchange
- Equipment Demonstrations
- Training on devices and issues related to accessibility and AT
- Presentations about ICAN and the benefits of technology
- Exhibits of AT
- Tours of the ICAN AT4ALL Clearinghouse
- Information resources like this website and our newsletter
- Technical Assistance to employers, service providers, educators, and others

The services offered by ICAN AT4ALL are available to all Arkansans, regardless of age, geographic area, disability, income or eligibility for any other services.

If you would like more information contact ICAN at 1-800-828-2799 or visit their website at www.ar-ican.org.

### Wheelchair Ads on TV

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9 years before you would qualify for a new wheelchair, once it is billed to your insurance, regardless of your situation.

A team evaluation, including a vendor ATP will assess your level of need for a wheelchair based on your ability, your home and community environment and your current or future medical needs. They will consider different brands and models of wheelchairs to meet those needs. An ATP is not there to sell you one of their "standard wheelchairs from their warehouse". The ATP will order a custom wheelchair designed and built for you to fit your unique needs, NOT make you fit into a wheelchair they have in stock in the warehouse. You may have to wait for the wheelchair to be built and delivered, but it will be your wheelchair.

Let's face it... a lot could happen in a few years that will make that WONDERFUL TV AD wheelchair obsolete for your medical needs.

By using a team approach when you are evaluated for a new wheelchair, you will receive input that takes a look at your medical needs from a long-standing basis. The old saying, "the more the merrier" comes to mind here. The team approach will look at why you need (there is a difference between want and need) the equipment, how you will transport the equipment, the pros and cons of power versus manual, as well as what you qualify for medically.

There is a lot to know about wheel-chairs in general and ensuring you select a vendor that will serve and stand by the product they provided to you is also key in selecting your vendor of choice...and you do have a choice!

You also need to keep in mind that

### **TAP Telecommunications Access Program**

TAP is a program within Arkansas Rehabilitation Services that provides free telephone equipment to eligible Arkansans who are deaf, hard of hearing, deafblind, or who have a speech, visual, mobility or cognitive impairment that prevents them from using a standard telephone.

Anyone who meets the following criteria can apply:

- Arkansas resident
- Personal telecommunication service
- Disability certified by a qualified professional that prohibits use of a standard telephone
- Income Eligibility: If your income is \$50,000 a year or below, the equipment is free and if you make more than \$50,000 a year, a shared cost option is available

Apply for TAP by downloading the application at:

http://ace.arkansas.gov/arRehabServices/programs/fieldServices/Pages/TelecommunicationsAccessProgram.aspx

To receive more information about the program please contact TAP at 1-800-981-4463.

majority of insurances (including Medicare and Medicaid) will only pay for a power OR a manual wheelchair and NOT both. If you get a power wheelchair, you cannot go back to a manual wheelchair later on. If you order a 'TV' power wheelchair thinking you will use it for long distances, you may never be able to get another 'everyday' lightweight manual chair again.

If in doubt, always discuss your need for a new wheelchair with your ASCC Case Manager. They can be a crucial member of the wheelchair evaluation team. They see and hear things from you that others do not, and that can make all the difference in that custom fit wheelchair versus a TV ad wheelchair.

Finally, remember that old adage:

If it sounds too good to be true, it probably is!

### CLIENT SPOTLIGHT

This is the first in a series of articles profiling people with spinal cord injuries that have returned to the workforce



John Perry, Jr. of Cabot, AR

Where do you work? AAFES (Army Air Force Exchange Services) in Jacksonville

What type of job do you have? Currently a greeter but soon starting to work in electronics

How long have you worked at this job? I've been employed for 12 years

How did you locate your job? H.I.R.E program / ARS

What type of state/federal benefits have you maintained? *Medicare/Medicaid and SSDI/SSI* 

What do you enjoy most about the job? Meeting a lot of interesting people from around the world

What do you enjoy least about the job? Dealing with difficult people who want to return items

What accommodations does your employer provide? Flexible work hours

How do you benefit by being employeed? It gives me a chance to get out of the house, meet other people, be productive, and feel independent

**How much support do your coworkers provide?** Very good and supportive, if I need anything they help me

What are your future goals?
To keep doing more work and expand my job duties

What is the most positive benefit since starting work? All the friends that I have met and the relationships that I have made while working at AAFES

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